Procedure for Using the Dementia Outcomes Care Planning Tool

The following guidelines are recommended by the providers who piloted this tool.

Who to Involve: This tool has had the most success when used collaboratively across all levels of an organization, and when all members of the care team had input.

- Providers of direct caregiving
- Supervisors of direct caregivers
- Nurses
- Managers or those who allocate resources
- Person with dementia
- Family members/guardians
- County/government care managers

Time Allocation: The processes involved in initial training on the tool and related good practice, and the initial care planning take time. The stakeholders in the process need to be able to make a time commitment up front for:

- Education of team members on good practices, especially direct caregivers supervisors and nurses (approximately four hours).
- Time for the team members to read and review the tool in its entirety (approximately two hours), while considering the person with dementia's needs.
- Collaborative planning meetings for team members to discuss and construct the care plans (suggested one - two hours per week).
- Ongoing, regular collaborative meetings to review progress and adjust care plans quarterly.

Initial training on good practices should involve direct caregivers, supervisors and nurses with the option of county care managers/social workers attending. Some agencies also involved the CEO/owner of the agency resulting in good support for implementing the outcomes. Team members reported reading the tool individually and then coming together as a group to discuss their recommendations and negotiate the care plan. Family members and persons with dementia were invited into a shorter discussion of the care plan options with the team as a follow-up.

Teams reported that the initial outlay of planning time resulted in a much smoother and more thorough process taking less time at subsequent meetings to review progress. Some agencies organized special activities for gaining information about the person with dementia over time such as family member discussion meetings, ongoing reminiscing activities for people with dementia (e.g., constructing personal story books), and direct caregiver sharing meetings.

(Document Number PDE-3195 Part 2)

Procedure for Using the Dementia Outcomes Care Planning Tool (continued)

What to focus on: It is suggested to begin with an overview of the entire set of outcomes and indicators to work with initially for each person, then choose a few indicators that may have the most impact. By prioritizing the indicators and asking for input from the family and person with dementia on establishing these priorities, there will be the greatest chance for successes that will provide momentum to continue the process.

Supportive good practice information and models: It is important that the people providing day to day care and allocating resources understand the good practice and how it relates to the indicators being measured. The agencies that piloted this tool received a four-hour training that included good practice concepts and referred to some specific resources as examples. A list of all of the items used in the training is found on the last page of this procedure. These are not intended to be all-inclusive, but are rather examples of how to implement some of the suggestions found in the best practice section of the tool. The extent of training needed will depend on the level of current knowledge providers already have. In general, these were the areas covered for the pilots to insure everyone had a baseline of knowledge:

- A special procedure for assessing pain and implementing a pain control regimen for persons with dementia who may be unable to communicate that they are in pain.
- A procedure for observing and documenting over at least a week's time the person with dementia, environment and behavior of others when behavioral symptoms are a problem needing to be addressed.
- Review of reversible/treatable causes of dementia symptoms, and medical issues that can exacerbate symptoms in persons with Alzheimer's disease and related dementia.
- Discussion of reasons why it is so important to get a good diagnostic work up from a dementia diagnostic specialist/clinic and how and where to access these services locally.
- Comparison and contrast between the use of parenting skills and Alzheimer's caregiving skills with communication and problem solving skill review.
- A structured, engaging, empowering model of activity programming.
- An assessment and suggestions for creating a dementia friendly environment.
- A review of the effects of trauma on someone with Alzheimer's disease.
- Strategies for working with people in different stages of Alzheimer's disease.
- Discussion of types of dementia other than Alzheimer's disease and strategies for working with individuals who have them.
- Review of the concept of person centered care, and definitions of outcomes, indicators and measures.

Procedure for Using the Dementia Outcomes Care Planning Tool (continued)

Care Planning and Implementing Changes: Recommendations from pilot agencies are to start small and implement changes in such a way that you can tell what is impacting the person's situation. Implementing too many things at once may lead to an inability to detect which strategies are having a positive effect and which are not. Make sure that everyone who works with the individual knows what the care plan is, how changes are being implemented and what to track to promote consistency. In situations where difficult behavior is being addressed, it may be necessary to have weekly meetings to assess progress and strategies until changes become routine. This is as much to support the staff as it is to support the person with dementia. Emphasize activities and processes that promote relationship building. It is as important to learn and share with everyone what is being done right as clearing the air on things that aren't successful. You need to do both.

Constructing the Care Plan:

1. Read through the Dementia Outcomes Care Planning Tool. Consider the issues that the person with dementia in your care may have.
2. Do an initial ranking of where the person may be on a scale of 1 to 5 for each of the indicators, then prioritize them in order of importance according to which outcomes and indicators may bring the best results if interventions are implemented.
3. Hold a team meeting to compare team perceptions and negotiate which outcomes and indicators are most relevant to work on.
4. Follow the example below on how to write the care plan.

Case Example:

Linda R. is an 86 year old widow who has lived at The Courtyard assisted living, an eight resident home, for two years. Although Linda seemed to have some problems with confusion when she first moved in, now it is becoming apparent that she has symptoms of dementia. Linda is more withdrawn lately, seems to be getting lost finding her room and has been found rummaging in other residents' drawers looking for pictures of her family. In the afternoon Linda seems upset and reports that she has to get home to make dinner for her kids and get ready for the girl-scout troop, which she led for 20 years, often at her home. Linda has been wearing the same clothes several days in a row and forgetting to wash lately too, which worries her daughters when they come to visit. Linda is often found sitting alone in her room staring out the window at the garden and nearby bird feeder when the daughters come to visit, unlike the way she was as a "social butterfly" with others when she first moved in. Linda seemed to change most six weeks ago when the activity therapist went out on maternity leave for three months. The Courtyard staff members have noticed over the last two weeks that Linda is still able to help in the kitchen when she is asked to and seems to enjoy it. The staff decide that the Dementia Outcomes Care Planning Tool may be helpful in providing ways to help Linda.

Here is what the Courtyard staff decided to include in Linda R.'s care plan.

Outcome #1
As a person with dementia, I have the best possible physical well being
Indicators:

1. **I am well hydrated**
2. **I am well nourished**
3. **I am comfortable – free from pain**
4. **I am physically active**
5. **I am clean**
6. **I am safe**
7. **My medical needs are being treated by people knowledgeable in dementia**
8. **I receive the least restrictive intervention for my behavior symptoms**

Indicator #1: The staff did not notice any changes in Linda's eating habits, but weren't sure about her fluid intake. However, with dehydration being a risk factor for afternoon agitation, staff decided to have the nurse test Linda's skin turgor and monitor her fluid intake for one week to see if she was getting enough in the afternoons to rule out dehydration. This trial did show that dehydration was a problem. Staff then asked Linda and her daughters to give them a list of Linda's favorite things to drink, and foods (like soup and watermelon) that are high in fluids. A schedule was then implemented to encourage Linda's fluid intake throughout the day to see if it made a difference in her afternoon mood.
Indicator #7: In order to rule out any other underlying medical and mental health issues, the staff decided to encourage the daughters to have Linda get a diagnostic work up at the local dementia clinic, since Linda had never had one.

Indicator #5: Linda being clean was the daughter's biggest concern. The staff observed Linda's morning routine and discovered that she was forgetting about the clothes in her closet because the door was closed, and she was putting on the first thing she saw in the morning - her dirty dress from the day before. She had also stopped wearing clothes that she had to put on over her head because it frightened her to do so when she was alone because she felt dizzy. Linda didn't wash or comb her hair because the new aid had been tidying up her room and putting away her hairbrush and face soap where she Linda couldn't see them when she was getting ready. The staff decided to add an evening routine where Linda was prompted to choose and lay out her clothes for the next day. In the morning staff added a prompt to Linda's routine where Linda was given her hairbrush, washcloth and soap to wash and get ready.

Linda responded well to these visual cues and was able to dress in clean clothes and get washed and ready with these minimal prompts. Staff found that an added result of the changes in routine to prompt fluids and spend a few minutes with Linda in the evening and morning, Linda and her caregivers also formed a more rewarding relationship.

Procedure for Using the Dementia Outcomes Care Planning Tool (continued)

Outcome #3:
As a person with dementia, I have hope because my future is valued and supported.
Indicators:

1. **I participate to my capacity in all decisions effecting my life**
2. **I am useful and make contributions of value**
3. **I plan and do things I've wanted to do while I still can**
4. **I have the emotional support and encouragement that I need**
5. **I have positive things to look forward to and do**
6. **I have a legally supported plan for my future needs and wishes**
7. **My previous wishes are honored as my capacity diminishes**
8. **I continue practices that nourish me spiritually**

Indicator #2: Linda seemed to enjoy contributing to the household by helping to prepare meals. It seemed to remind her of the preparations she made to host the girl-scout troop she led for 20 years. The staff decided to incorporate this into Linda's routine to see if it could minimize the upset mood she seemed to get into in the late afternoons. The daughters were invited to bring Linda's memorabilia on her girl-scout days to the home and they and Linda reminisced about all of the activities they did together as girl scouts. This gave staff a wealth of information to draw from in setting up a late afternoon activity for Linda and other residents. Linda helped prepare for the activity, helped to lead the group and helped with the meal regularly, and peer relationships developed between the residents who were participating.

There is a separate attachment of sample page from Linda's care plan outlining the information from Outcomes #1 and #3.

Dementia Outcomes Care Planning Tool Good Practices Resource List

This is a list of resources that were used for training Dementia Outcomes Care Planning Tool pilot sites. They are meant to be suggestions and do not constitute an all-inclusive list of potential resources.

1. **Procedures for observing and documenting behavior and environment.**
   - "Alzheimer's Disease Activity Focused Care". Helen, Carly. Butterworth, Heinemann, Boston, MA; 1998. Has excellent examples of forms, discussions of ways to empower staff and how meetings about observations should be held.

   - "Creating Successful Dementia Care Settings". Calkins, Margaret P., Perez, Kristin, Proffitt, Mark – "Volume three – Minimizing Disruptive Behaviors" video and book (from a four volume and three video training set) by Innovative Designs in Environments for an Aging Society (IDEAS) 888-337-8808; Health Professions Press, 2001.

2. **A structured, engaging, empowering model of activity programming.**
   - "Rekindling the Spark of Life – Joyful Activities for People with Dementia" Video and
     Training Manual Set. Verity, Jane, Dementia Care Australia; 1999 www.DementiaCareAustralia.com This Is an excellent resource for developing a club approach to activity programming. Ms. Verity studied with Thomas Kitwood and has an actual formula of person centered approaches that bring people with dementia to life. Highly recommended along with her web site that has numerous activity products.

3. **Procedure for assessing pain and implementing a pain control regimen for persons with Dementia.**
   - "Improving Management of Physical Pain and Affective Discomfort for People with Dementia in Long Term Care – The Assessment of Discomfort in Dementia Protocol (ADD)" Kovach, Christine PhD, RN, et al: Marquette University College of Nursing, Milwaukee, Wisconsin; 1997. Contact University of Wisconsin Center for Age and Community at 414-229-2740, www.uwm.edu/Dept/ageandcommunity/ Or Cathy Kehoe 608-267-2439 kehoecb@dhfs.state.wi.us.

4. **Comparison and contrast between the use of parenting skills and Alzheimer's caregiving skills with communication and problem solving skill review.**
   - "Changing Our Minds: From Parenting to Caregiving A Mentoring Tool for Alzheimer's Caregivers Training Manual" Kehoe,C. WI Dept of health and Family Services, Madison, Wisconsin; 2001. Available on DHFS web site at: www.dhfs.wisconsonsin.gov/againg/genage/alzfc.htm, or from Cathy Kehoe 608-267-2439 kehoecb@dhfs.state.wi.us.

Dementia Outcomes Care Planning Tool Good Practices Resource List (Continued)

5. Strategies for working with people in different stages of Alzheimer's disease.

- "Alzheimer's Disease: Inside Looking Out". Video Terra Nova Films 800-779-8491, www.terranova.com. Good depiction of people in early stages of Alzheimer's disease.

- "Communicating with Moderately Confused Older Adults". Video Training Series
- "Communicating with Severely Confused Older Adults". Miller-Dwan Foundation; 1998. Both videos available through Terra Nova Films (1-800-779-8491). The first video covers working with people in middle stages of Alzheimer's disease and second is later stages.

5. An assessment and suggestions for creating a dementia friendly environment.

- "The Complete Guide to Alzheimer's Proofing Your Home". Warner, M., Ageless Design; 2001 (Available through the Alzheimer's Store 800-752-3238 or www.alzstore.com)
  Another excellent resource, as are the ingenious adaptive aids on the web site.

- **"Planning Guide for Dementia Care at Home a Reference Tool for Care Managers"**. and accompanying "Alzheimer's Disease Home Safety Assessment." Developed by WI Department of health and family Services, Wisconsin Alzheimer's Institute and The Alzheimer's Association South Central Wisconsin Chapter, 2003. Available on DHFS web site at: www.dhfs.wisconsonsin.gov/againg/genage/alzfc.htm, or from Cathy Kehoe 608-267-2439 kehoecb@dhfs.state.wi.us.

- **"Designing the Physical Environment for Persons with Dementia".**
  Audiovisual presentation The Wesley Hall Alzheimer's Disease Project two Year Demonstration Project Chelsea United Methodist Retirement Home Chelsea, MI University of Michigan Institute of Gerontology The Regents of the University of Michigan 1987. Available through Terra Nova Films. This has good principles for developing or converting to a dementia friendly facility.

6. Review of the concept of person centered care

- "Dementia Reconsidered". Kitwood, Tom. Open University Press, Buckingham, England; 1997. Also, the work of The Bradford Dementia Group who has continued Tom Kitwood's work, and their "Well Being and Ill Being Profile" tool developed by Errolyn Bruce. Bradford University School for Health Studies, Unity Building, 25 Trinity Road Little Horton, Bradford BD5 0BB. http://www.brad.ac.uk/acad/health/bdg/.

Project Description: Dementia Quality of Life Outcomes

As part of the State of Wisconsin's initiative to improve services for people with dementia in the community based long term care system, an advisory committee was formed to define quality of life outcomes important to people with dementia. From March through June 2002, the committee met for six full day working sessions. Committee members identified seven core outcomes with related indicators, measures and suggestions supporting good practice. The committee was comprised of 23 experts representing each service field of dementia care and region of the state, and included two dementia family caregivers and a consumer in the early stages of Alzheimer's disease.

The ***Dementia Quality of Life Outcomes Care Planning Tool for Providers*** is the result of the committee's work to develop a tool that would guide providers to plan ways of supporting the best quality of life possible for people suffering from Alzheimer's disease and related dementia. The future direction of the project includes dissemination and use of these outcomes as a means to collaborate and coordinate interdisciplinary care for individuals across systems and providers in Wisconsin's community based long-term care system.

Advisory Committee Members

1. Phyllis Blackburn Director Milwaukee Community Dementia Service Bank
St. Ann Center for Intergenerational Care Inc., Milwaukee WI.
Day services, in-home services, respite. (Southeastern region)

2. Sue Blount Regional Field Operations Supervisor
Southern Regional Office, WI Bureau of Quality Assurance.
Madison WI. Licensing and compliance in residential facilities.
(Southern region)

3. Rose Boron President Wisconsin Elder Alliance LLC, Mosinee WI.
Long term care consultant and former assisted living provider.
(Northern region)

4. Heather Bruemmeer Regional Long Term Care Ombudsman, Wisconsin Board on Aging and Long Term Care, Green Bay WI.
Long term care resident advocacy. (Northeastern region)

5. Robin Ecoff RN Care Manager Waukesha County Department of Health and Human Services, Waukesha WI. (Retired). County community based care management. (Southeastern region)

6. Dorrae Fietz	Adult Day Services Provider Holy Family Memorial Adult Day Services, Manitowoc WI. (Northeast region)
7. Monica Froh	Quality Assurance Consultant The Management Group, Madison WI. County care plan monitoring and review of community based long term care services. (Statewide focus)
8. Nancy Holtz	Executive Director, Interfaith Volunteer Coordinator ABC Connections, Portage WI. (Southern region)
9. Noreen Kuroski	Director Monroe County Senior Services County based senior services and senior center. Sparta WI. (Western region)
10. Barbara Lawrence	BSN MS Senior Outreach Specialist, University of Wisconsin Medical School Wisconsin Alzheimer's Institute, Madison WI. (Statewide focus)
11. Kim Marheine	Program Director Alzheimer's Association of Greater Wisconsin, Neenah WI. (Northern region)
12. Alice Mirk	Family Care Implementation and Technical Assistance Manager WI Department of Health and Family Services Office of Strategic Finance, Center for Delivery Systems Development (Statewide focus)
13. Bob Nichols	Attorney, retired. Consumer and advocate. Green Bay WI (Northeast region)
14. Dennie Nichols	Family Caregiver, Corporate Guardianship Specialist Professional Guardianships Green Bay WI (Northeast region)
15. Mary Pike	Family Caregiver, Volunteer & Board Member South Central WI Alzheimer's Association, Madison WI. (Southern Region)
16. Dianne Rhein	Regional Planner, Program Consultant AgeAdvantAge Area Agency on Aging, Altoona WI. (Western Region)

17. Carolyn Schuleine Social Worker/Adult Family Home Coordinator, Community Support Program, Wood County Unified Services Marshfield WI. Recruiting and support of small home-style care providers. (Northern region)

18. Kathy Vite-Hazelton CSW, Social Worker - CCO
Aging and Disability Resource Center of Kenosha County Kenosha WI. (Southeastern region)

19. Patrick Vohen RN, Alzheimer's Community Resources Committee Vice Chair, Director of Community Based Residential Facilities & Assisted Living Services, Beaver Dam Community Hospital Remembrance Home, Beaver Dam WI. (Southern region)

20. Donna McDowell Director, Wisconsin Bureau of Aging and Long Term Care Resources, Madison WI. (Statewide focus)

21. Cathy Kehoe Alzheimer's Service Developer, Wisconsin Bureau of Aging and Long Term Care Resources, Madison WI. (Statewide focus)

22. Lora Warner Ph.D. Consultant for Project. President, Planning and Evaluation Associates; Professor University of WI Green Bay.

Questions and comments about this project or the use of the ***Dementia Quality of Life Outcomes Care Planning Tool for Providers*** may be directed to:

Cathy Kehoe, Alzheimer's Service Developer
WI Department of Health and Family Services
1 West Wilson Street, PO Box 7851
Madison, WI 53707-7851
Office: 608-267-2439
Fax: 608-267-3203
kehoecb@dhfs.state.wi.us

Please see the Wisconsin Department of Health and Family Services web site for additional information, materials and resources on dementia care:
http://dhfs.wisconsin.gov/aging/genage/alzfcgsp.htm